

✧ RESEARCH PAPER ✧

Care demands on mothers caring for a child with Down syndrome: Malaysian (Sarawak) mothers' perspectives

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Accepted for publication August 2013

Chan KG, Lim KA, Ling HK. *International Journal of Nursing Practice* 2014; ••: ••–••

Care demands on mothers caring for a child with Down syndrome: Malaysian (Sarawak) mothers' perspectives

This paper examines the experiences of mothers caring for a child with Down syndrome in the Malaysian (Sarawak) context. Qualitative interviews were conducted with 26 biological mothers of children with Down syndrome aged 18 years and below. They were accessed through selected child health clinics, community-based rehabilitation centres and schools using purposive sampling within two regions in Sarawak, one of the two Borneo States of Malaysia. Major themes emerging within the context of care demands were children's health, developmental delays, daily needs and behaviour issues. The insights obtained into the care demands experienced by mothers of children with Down syndrome have several implications for practice by care professionals.

Key words: behaviour, care demands, child, Down syndrome, experiences of mothers.

INTRODUCTION

Mothering a child has widely been described as a challenging task.^{1–3} The question thus arises as to what it is like for

a mother to have a child with a disability. Motherhood of a child with a disability such as Down syndrome (DS) can be especially challenging and demanding. DS, a common genetic disorder, is caused by an extra 21st chromosome.⁴ Children who are born with this condition are often affected by congenital cardiac, gastrointestinal or other anomalies that require urgent care and treatment in the hospital immediately after delivery and subsequent medical follow-up.⁵ Besides this, DS in children is frequently associated with a variety of developmental delays and impairments (social, language, self-help, cognitive and psychomotor).⁶

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At the national level in Malaysia, more than 600 new cases of DS in children are reported annually. These cases constitute almost a quarter of the total number of cases of disability in children below 12 years old reported each year.⁷ Children with DS and their parents are thus a significant group in Malaysia (including Sarawak) and worthy of research attention.

Previous studies have revealed that mothers of children with DS face a variety of challenges throughout their children's lives.^{4,8–13} They might experience difficult emotions such as grief, depression, guilt and self-blame.^{14,15} Their parental function can be affected due to stress and pessimism about the future.¹¹ The burden of caring for children with DS has been reported to contribute to maternal stress.¹⁶

According to the Resiliency Model of Family Stress, Adjustment and Adaptation,¹⁷ successful family adaptation in a challenging situation such as the need to care for a child with disability can be considered to have occurred when the family is able to achieve a balance among the family resources, the needs of the child and the needs of the family as a whole. High levels of parental well-being and overall family functioning suggest successful adaptation. Family resiliency is the ability of a family to respond positively to an adverse event and emerge strengthened, more resourceful and confident.¹⁷ This resilience or adaptation is fostered by *protective factors* (e.g. availability of family resources) and inhibited by *risk factors* (e.g. lack of family resources). *Protective factors* modify or transform responses to adverse events so that families avoid possible negative outcomes. Conversely, *risk factors* are circumstances that increase the probability of poor outcomes. Protective and risk factors are not static entities but dynamic ones, as they change in relation to context.¹⁸

Most previous studies on the experiences of mothers or parents of children with disabilities such as DS have been conducted in Western, developed countries. Thus, their results might not be relevant to a culturally contrasting country such as Malaysia. Furthermore, geographical remoteness, relatively undeveloped infrastructure and public transport systems, and lack of access to service provision are issues of concern for many rural communities in Malaysia.¹⁹ There have been only a few local studies on children with disabilities and their parents.^{20–22} In particular, detailed accounts of the experiences of mothers caring for children with DS in the state of Sarawak are very few. Therefore, the purpose of the study was to investigate the experiences of Malaysian (Sarawak)

mothers caring for a child with DS. The main research question that guided the study was 'What are the experiences of Malaysian (Sarawak) mothers caring for a child with DS?'

The focus was on exploring the experiences of mothers caring for children with DS with regard to their children's needs, behavioural characteristics and development within the local sociocultural and environmental context. This paper, which focuses on the *care demands* placed on mothers in the course of caregiving, constitutes part of a larger study. Insights into their experiences will supplement existing knowledge related to mothering of children in the socioeconomically and culturally diverse context of Malaysia and Sarawak. The significant findings presented by this study regarding the perspectives of mothers of children with DS highlight and draw attention to the various care concerns faced by these mothers.

METHODS

A qualitative approach was adopted to answer the main research question regarding mothers' experiences of caring for children with DS in order to provide the in-depth data necessary to answer the research question.^{23,24} The many aspects of these mothers' caregiving experiences were explored using qualitative interviews. The interviews were conducted in a manner that sought and valued interviewees' perspectives on or experience of social reality through their constructed interpretations or definitions of it. The researcher sought to gain an understanding of each interviewee's perspective in a language that was natural to the interviewee.²⁵

Study setting and recruitment of participants

Biological mothers of children with DS aged 18 years and below who consented to participate were recruited for the study based on their firsthand experience of caregiving. Non-probability, purposive sampling was used to recruit participants. To ensure maximum variation in participants' experiences, the participants recruited were of various ethnicities and from both rural and urban localities. Registers of names of children attending three community-based rehabilitation centres, three child health clinics, one government school and one non-government school were screened as a way to access their mothers and recruit them as participants. In addition, four

mothers with a child with DS who was not attending any of these organisations were also recruited through informal sources.

Sample size was determined by data saturation. Interviews were stopped when no new theme could be derived from the data, which were then deemed rich and dense enough for an in-depth understanding of the topic. In qualitative research, a small sample size can be adequate to allow in-depth analysis to provide a new and deeper understanding of the topic.²⁶ A previous qualitative study that explored the experiences of mothers of children with DS had a smaller number of participants than this one ($n = 18$).¹¹

Ethical considerations

Conducting research that involves a potentially sensitive topic requires diligent attention to ethical principles such as respect, autonomy and confidentiality. After ethics approval was obtained from the gatekeepers of the various organisations concerned, relevant details were obtained from these organisations, enabling access to and identification of potential participants. A series of informal meetings with the senior personnel of these institutions assisted in gaining organisational support and indirectly helped in the recruitment of participants.

To avoid any coercion, only mothers who had returned the reply slips indicating their willingness to participate in the study were contacted. Information about the nature of the study, its objectives and the method of data collection was given to the potential participants in English, Bahasa Malaysia and Mandarin by the first author, who conducted the interviews. For those who were illiterate, verbal explanations in the language they understood were provided. Consent for participation was obtained after potential interviewees had been fully and openly informed regarding what the study would involve. They were informed that participation was voluntary and that they were free to end the interview session at any time they desired. They were assured of anonymity and of the confidentiality of all information they might give.

The process of interviewing the mothers, which provided a space for them to talk about their experiences, could be therapeutic; however, the first author, who conducted the interviews, was aware of the potential risk of psychological discomfort for participants revisiting their experiences. Contact details of local counselling services and parent support groups were ready at hand so they could be offered to participants if necessary. In instances

where participants became emotional as they shared their experiences, the author maintained an attitude of concern, listening attentively to them while trying not to be overly reactive to their displays of emotion.

Data collection

Mothers who consented were interviewed face to face and audio-recorded in their own homes within the period from May 2008 to July 2009. Interviews, each lasting from about one and a half to two and a half hours, were conducted in English, Bahasa Malaysia (the Malaysian national language), Iban language, Mandarin language or Hokkien dialect. The majority of interviewees consented to be re-interviewed within one week after the initial interviews for verification of the data and to clarify any questions arising from the previous interviews.

Data management and data analysis

Translated verbatim transcripts were verified by a bilingual language expert. Textual data from interview transcripts were managed and analysed with NVivo 7.0, a computer-assisted qualitative data analysis software (CAQDAS) program.²⁷ Thematic analysis guided by Creswell's six generic steps of data analysis was conducted.²³ This involved preparing and organising textual data for analysis, reading through textual data, coding to generate themes, representation of themes and interpretation. Themes and subthemes representing the many aspects of mothers' caregiving experiences were identified. Review of the identified themes and subthemes by two university lecturers with expertise in qualitative data analysis enhanced the interpretive rigor.

RESULTS

Participants' background characteristics

Twenty-six mothers were recruited for the study (Table 1). The mothers' ages ranged from 22 to 44 years, with a mean age (in years) of 42.44 ± 8.35 . The mean age of their children with DS (in years) was 7.4 ± 5.0 . They lived in various geographical locations, mainly in the capital city of Kuching and in a semi-rural region 40 km outside Kuching in the Samarahan Division. They were from socioeconomically and culturally diverse backgrounds, consisting mainly of Ibans, Chinese, Malays and Bidayus, representing the main ethnic groups in Sarawak. The majority of participants were married and lived with their husbands, except for two participants who were single mothers and lived with extended family.

Table 1 Participants' background characteristics ($n = 26$)

	n (%)
Locality	
Rural	11 (42.3)
Urban	15 (57.7)
Ethnicity	
Malay	9 (34.6)
Chinese	9 (34.6)
Iban	5 (23.1)
Bidayuh	3 (7.7)
Religion	
Islam	9 (34.6)
Christianity	11 (40.7)
Buddhism	6 (22.2)
Marital status	
Married	24 (92.3)
Single	2 (7.7)
Highest educational level	
No education	3 (11.5)
Primary school education	7 (26.9)
Secondary school education	13 (50.0)
Tertiary education	3 (11.5)
Employment status	
Unemployed (housewife)	15 (57.7)
Employed	11 (42.3)
Household income	
RM500 and below	4 (15.4)
RM501–1000	8 (30.8)
RM1001–2000	6 (23.1)
RM2000 and above	8 (30.8)
Family transport	
Car	16 (61.5)
Motorcycle	8 (30.8)
Public transport	2 (7.7)
Mother's age (years), mean \pm SD (range)	42.4 \pm 8.4 (23–61)
Mother's age (years) at birth of child	34.5 \pm 5.7 (22–44)
with DS, mean \pm SD (range)	
Age of child with DS, mean \pm SD (range)	7.4 \pm 5.0 (1–17)

More than one-third of participants (38.4%; $n = 10$) had only a primary school education or below; 15.4% ($n = 4$) reported a monthly household income of RM500 (US\$159.60) or below; slightly more than half were housewives; most were the primary caregivers of their DS children, with the support of their husbands and other children, whereas a few had access to their extended families, and three working mothers employed staying-in-house helpers to support them in caregiving.

The care demands placed on the mothers are presented according to four subthemes; specifically, care demands were related to child health, developmental delay, daily needs and behaviour. These subthemes are illustrated by quotes of mothers' own words, providing rich and detailed descriptions of mothers' experiences and allowing the reader to judge the data interpretation. The names of mothers as reported below are pseudonyms.

Subtheme 1: Child health-related care demands

For many of the mothers, congenital conditions contributed to care demands, especially during the early stages of their children's lives. These included cardiac conditions that required intensive care. Several children also required cardiac surgery one to two years after birth. In some cases, acute congenital gastrointestinal conditions such as Hirschsprung's disease and duodenal atresia necessitated surgery soon after birth, followed by days of intensive incubator care.

Care demands related to their children's health affected some of the mothers' working lives and their availability for their other children. Adrina, one of the mothers, described her life as 'hectic', as she had to juggle working during the day and taking care of her child at night when her child was hospitalized for leukaemia and a lung infection.

Health-related care demands were physically taxing. One mother, Salina, described her experience with her daughter:

Even sleeping at night was difficult. Often my husband and I took turns to sleep. If we didn't hold her, she would cry. Sometimes, I myself cried seeing that she kept crying and could not keep quiet. I didn't know what to do. Eventually we had to send her to hospital, sometimes at 1 or 2 AM in the night.

Subtheme 2: Developmental delay-related care demands

Care demands related to children's developmental delay required mothers to expend much effort and time. This included the effort of seeking various interventional therapies and treatments. Their efforts and time were spent in trying to communicate with their children, in helping their children to learn and in watching over their children's safety.

Many of the mothers sought therapies and treatment such as physiotherapy, speech therapy or traditional treatments. These were sought from a variety of services, depending on which services they thought would be most helpful for their children. One mother, Kay, related her day-to-day experience during the early stages of her child's life:

At two years old, she was still moving using her buttock and still could not walk. At four or five years old she still could not talk. At that time we brought her for physiotherapy every Tuesday. We sent her to the community-based rehabilitation centre once a month and also for speech therapy. We heard about a church which provided an early intervention program so we sent her there. We rushed to bring her here and there for treatment.

The level of intensity of care demands was evident for those mothers who sought treatment of one form or another, seeking help not only from modern medicine but also from traditional treatments. It is interesting to note that this treatment-seeking cut across ethnic and geographical boundaries. For example, Daniela, a mother of Chinese ethnicity from Kuching, described her experience during the first few years of her son's life:

Someone suggested that I look for a temple medium for him. I went. I also brought him to places like Saratok and Sarikei [two small towns in Sarawak] to look for the Iban [one of the main ethnic groups] people who knew about traditional medicine. I also looked for the Chinese 'sin seh' [traditional massage therapist] who could massage him.

The issues arising from this common experience of mothers seeking treatment across ethnic boundaries will be explored in the Discussion section.

Difficulty in communicating with and understanding their children's needs brought many challenges for the mothers in their daily caregiving. Julia expressed her frustration with communication with her 8-year-old boy:

You actually didn't know what he wanted. He would cry the whole night; cry and cry, very demanding and stubborn. He would not speak; ah, very frustrating.

As for Daniela, she indicated that her 3-year-old son often had to 'scream loudly' to express that he wanted

something and that this was tiring for her. She expressed her difficulty in trying to teach him. She struggled with her son's non-purposeful activities such as scribbling and his short attention span, inattentiveness and unresponsiveness during the time when she wanted to teach him.

Due to her child's developmental delay in learning, the level of care demanded of Jen, a Chinese mother of a 3-year-old boy, in teaching her child was immense:

I tried to teach him a bit of alphabet; I had to keep on teaching him and reminding him; if I missed a week, he would forget.

For many of the mothers, the constant need to watch over and protect their children for their own safety was physically and mentally exhausting. Kay, a mother of a 9-year-old girl, recounted an incident when she almost lost track of her child, who wandered away from her:

One day, she was almost lost in the supermarket. We were together inside the lift. When the lift opened, she just slipped out by herself. I had to rush out to look for her. Later, I found her squatting at the shop.

Farah, the mother of a 16-year-old teenage girl, talked about the need to constantly keep her child under her watchful eyes:

Once, we were walking together outside the house. Suddenly I didn't know where she had walked to. I went around the whole housing area searching for her. Finally, I found her in the police station. That is why I prefer her to stay at home and not let her go out by herself. I take her out on Saturdays or Sundays only.

Aziah, a Malay mother, constantly watched over her 5-year-old girl, as she was concerned her child might follow any stranger due to her child's lack of social inhibition or fear of strangers. Her house's front door had to be locked all the time due to her fear that her daughter might go outside the house, which was near the roadside. (This lack of social inhibition was evidenced during the first author's visit to Aziah's home, as the daughter brought her pillow, came close to him and went to sleep on the settee next to where he sat. She even placed her legs on his lap while he was sitting on the settee with her mother. This was despite his being a stranger to this girl.)

Subtheme 3: Daily needs-related care demands

Meeting children's daily needs, especially during meal times, and meeting their toileting and physiological needs contributed significantly to care demands on mothers. Caregiving during their children's meal times could be frustrating for some of the mothers, as their children were uncooperative. Daniela's description of meal times with her 3-year-old boy is illustrative:

He liked to play with rice during meal times. When I asked him not to, he refused to listen; very stubborn.

When children had delayed bowel control, the level of care demands incurred was significant, as described by Aziah, who had a 5-year-old girl:

I have to wash her buttocks. I feel like crying when I see her like this. She can't tell me when she wants to pass a motion. Only sometimes she can. 'Half dead' [denotes physically exhausted in the local context] taking care of her. Sometimes, halfway eating or sleeping, just about to sit down, or halfway through doing my work, I have to leave everything aside [just to attend to the child].

There were mothers who were concerned about their teenage daughters who had started their menstrual flow and yet could not manage their self-care needs. Hazlin's quote below, about her 13-year-old daughter, is illustrative of their concern:

The most challenging part was when she had her period. She could not use sanitary pads by herself yet. The others could see the blood stains on her pants as she walked here and there.

Subtheme 4: Behaviour-related care demands

Children's personal and social behavioural characteristics, such as throwing tantrums, being extra active, and displaying behaviours that were socially or age-inappropriate or disruptive, clearly contributed to mothers' experiences of care demands. Such care demands were physically exhausting, as Normirah illustrated in describing her experience with her 4-year-old girl:

I feel so stressed. She is just so active. Once the house door is opened, she runs outside. One day, when I was in the clinic with her, she pulled and toppled the stand fan and caused

other children to cry. She throws everything she sees (sigh). I have to look after this child 24 hours a day. It is only when she sleeps that it is ok.

During the interview with Normirah, her 4-year-old daughter came near the first author and abruptly pulled off his spectacles, bending one side out of shape. Normirah was apologetic about it. The author observed the child trying to climb up the wooden shelf to reach the TV set but being stopped by her father. Later, she threw her toys out the window. She tried to pull the author's MP3 recorder from his hands but was restrained by her mother.

In relation to children's behaviours, apparently several of the mothers had difficulty setting limits or imposing discipline. Kay related an incident when she took her 9-year-old girl to the supermarket:

It is really tough. She is very stubborn. She refused to leave that place. I did not know what to do. She put her two hands inside her pockets, jumped like a frog, step by step down the staircase. People walked about at the supermarket . . . it's so embarrassing. But I can't insist that she listens to me. I pity her. Honestly, I follow her way. I regard her as a 'special' child, feeling guilty to raise my voice.

The various care demands related to health conditions, delays in development, daily needs and behavioural concerns apparently contributed to mothers' fatigue, both physical and mental.

DISCUSSION

In the course of caring for their children with DS, mothers experienced extra care demands, starting soon after their children's birth, due to their children's health condition. They sacrificed their own comfort to meet their children's needs.^{1,28} Mothers' concerns about their children's vulnerability to harm and dangers due to their lack of social inhibitions or fear of strangers resulted in mothers constantly taking precautionary measures to watch over their children. Furthermore, for those mothers with daughters who had reached puberty with the associated physiological development, including the starting of the normal monthly menstrual cycle, the need to help their children with self-care presented additional challenges.²⁹ Mothers' experiences of extra care demands due to having to assist their children at meal times or with going to the toilet and difficulties in communicating with their children due to

their children's lack of understanding or communication abilities have been highlighted in a previous article.³⁰ Experiences of care demands and related stress have been reported in a number of existing studies; however, most of them lack in-depth qualitative detail.^{31–39} The present study illuminates and helps to provide insights into the experience of providing care to a child with DS.

The local social context has been reported as seemingly unsupportive (Chataika T., unpubl. data, 2009) and critical of children with disabilities or of their mothers. This could be related to traditional cultural beliefs existing among specific ethnic groups. In particular, contributing beliefs might include beliefs that the birth of a child with disabilities is due to bad 'feng shui', a family curse, spirits or punishment for wrong acts by the mothers.²⁰ These beliefs could indirectly influence societal perceptions and acceptance or rejection of a child with a disability and his or her mother. This could lead to variations in the level of informal support, such as in the quality of extended family support for some mothers, within the multiethnic Malaysian context. This could result in poorer well-being for those mothers who have to meet the care demands of a child with DS.

On the other hand, religious beliefs and convictions among some of the Muslim and Christian mothers might positively influence their perceptions and acceptance of having a child with a disability. These could include beliefs and convictions that the child is God's gift and 'predestined with a divine purpose'. This might assist them to gain a sense of confidence and hope. Although, as noted in an earlier study,⁴⁰ this view is changing, nevertheless it might explain why, in some Muslim communities, a disabled child is not stigmatised and the parents do not experience community discrimination. Such beliefs could have a positive influence on mothers' well-being as they try to meet the care demands of a child with DS.

Another sociocultural issue worthy of highlighting is mothers' experiences of seeking treatment for their child through traditional approaches, spanning ethnic and cultural divides, as mentioned in the Results section. This is very similar to the experiences of people seeking treatment for family members with mental health problems, as noted in several studies in Sarawak and Malaysia.^{41,42} Not only does trying a variety of treatment approaches serve to relieve the family or mentally ill person of shame and guilt, but sometimes the treatment approaches bring the person closer to the community.⁴⁰ However, in the case of families or mothers of children with DS as in this study,

such a 'benefit' has not been reported or been evidenced. Interview data from the mothers pointed to increased physical and mental demand associated with this search for treatments, which sometimes entailed travelling to different regions of Sarawak. Although traditional treatments do not incur a high cost, as the amount of payment is decided by the help-seekers, travelling costs can put a strain on the economic resources of families from lower-income backgrounds. Nevertheless, the seeking of treatment from various sources seemed to provide mothers with hope and strength to move ahead with life.

Another noteworthy aspect of mothers' caregiving experiences is related to management of their children's behaviours. Apparently, among these mothers, there was a struggle with a feeling of guilt when they imposed limits or 'discipline' on their children. This was due to perceptions that their discipline had little impact, as their children were unresponsive to it, or that their children with DS were 'special', leading to them feeling pity for their children. Thus, they would not discipline their DS child as they would their other children. Difficulties in setting limits or imposing discipline in response to challenging behaviours could be due to mothers' underestimation of their children's potential.⁴³

There is an indication that mothers of DS children need to be empowered. Such empowerment would involve equipping them with particular parenting skills and providing formal support in order to enhance their preparedness to assist in their children's development and to exercise 'assertive discipline and have realistic expectations'.³⁰ It is emphasized that unacceptable behaviours can recur due to unhelpful beliefs on the part of the caregivers, such as the belief that they could not respond proactively due to their children's disability.⁴⁴ The president of the National Early Childhood Intervention Council (NECIC) (Malaysia) has highlighted the significance of parental preparedness in his vision for society 'to offer concrete action to help the children'.⁴⁵ In this regard, national organizations such as the NECIC and other support groups offer relevant programs through workshops or conferences such as the 4th NECIC Conference.⁴⁶ However, some mothers have difficulty in accessing services due to literacy problems or geographical distance from services. For these or other reasons, their children do not have access to any of the existing service programmes and remain a group who are particularly disadvantaged.

In this study, it has been shown that mothering children with disabilities such as DS is clearly challenging and

demanding due to the children's health conditions, developmental delay, daily needs, and personal and social behavioural characteristics. As they have to meet various care demands that cost time and effort, it is important that mothers have access to a range of support. As stated previously, the availability of various types of support is one type of family resource—one of the 'protective factors' that foster family adaptation to a challenging situation such as having a child with disability in the family. On the other hand, the lack of this family resource of the needed support is a risk factor that could inhibit adaptation and result in poorer well-being for mothers.¹⁷

The implications of the study findings for the planning and delivery of health care provision and for the nursing profession with regard to providing appropriate support services warrant serious consideration.

Conclusion

Care demands related to the health conditions, delayed development, daily needs, and social and behavioural characteristics of children with DS cost extra time and effort for mothers at different stages of their mothering journeys. It is beyond question that caring for children with DS is challenging and demanding. The findings provide further insight into the experiences of mothers in the Sarawak region. It will be beneficial for care professionals such as nurses, doctors, therapists, social welfare workers and teachers to be well informed regarding these various care demands. Care professionals, in providing care to children with DS and their mothers, need to have great sensitivity and responsiveness to these various care demands that mothers might encounter in the course of their children's lives. The findings suggest that mothers of DS children will be able to provide more effective care if they are assured of having access to a range of support systems. This will empower them in their caregiving tasks. Furthermore, there is a role for a platform for sharing experiences of challenges, concerns and practical knowledge on various aspects of care among parents of children with DS (especially mothers) and professionals.

ACKNOWLEDGEMENTS

The authors wish to express their special thanks and appreciation to the Sarawak State Health Department, Malaysia Ministry of Education, Sarawak Social Welfare Department and Sarawak State Planning Unit for the kind approval to access the various organisations through which mothers were recruited as participants for the study.

Special thanks and appreciation are extended to the staff of the various community-based rehabilitation centres, health clinics and schools for their support and assistance in facilitating access to participants. We would like to thank the University of Malaya for granting the post-graduate research funding (grant number IPPP/UPDiT/Geran (PPP)/PS171/2008C) during the conduct of the study. Our sincere thanks to all the mothers for sharing their experiences; without them this study would not have been possible. We would also like to thank Colin Smith (Department of Communities, Child Safety & Disability Services, Caloundra, Queensland, Australia) for his editorial services.

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